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Effect of palliative care nurse champions on the quality of dying in the hospital according to bereaved relatives: a controlled before and after study

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What is already known about this topic?

Patients dying in the hospital have many unmet needs, such as insufficient symptom control and communication.

Innovative experimental studies are scarce but needed, to evaluate whether changes in structures, processes and competencies in palliative care affect patient or relative outcomes.

Measuring the effects of complex interventions in palliative care involves many methodological and ethical challenges.

What this paper adds?

We performed a controlled before and after study with a complex intervention on palliative care nurse champions, on the effects on the quality of dying as experienced by relatives.

We neither found improving effects of palliative care nurse champions on relative reported outcomes on the quality of dying in the hospital, nor a worsening, as was seen in the control wards.

We discussed factors that might have contributed to our equal outcomes pre- and post-intervention, such as the research methodology and the role of nurses in hospital end-of-life care.

Implications for practice, theory or policy?

We showed that experimental research in the organisation of end-of-life care is feasible but needs a well-prepared study design and process.

An intervention with palliative care nurse champions to improve hospital end-of-life care is promising on condition of increased competencies and empowerment of nurses, and the support from palliative care experts, and ward staff and management.

Abstract

Background: To improve the quality of end-of-life care, hospitals increasingly appoint palliative care nurse champions.

Aim: We investigated the effect of nurse champions on the quality of life during the last three days of life (QOL3) and the quality of dying (QOD) as experienced by bereaved relatives.

Design: A controlled before and after study (June 2009-July 2012). Halfway, in each of 7 intervention wards two nurse champions were appointed; 11 wards served as control wards. The QOL3, QOD, and multiple dimensions of QOD, were compared before and after the introduction of nurse champions.

Setting: In a university hospital each death at non-intensive care units was followed by an invitation to relatives (10-13 weeks later) to answer a questionnaire.

Results: For the two periods, data were collected on 86 and 84 patients in intervention wards, and on 108 and 118 patients in control wards (overall response 52%). In the intervention wards, no differences were found in QOL3 and QOD scores: in both periods, median score for QOL3 was 3.0 and for QOD 7.0. No differences were found in multiple QOD dimensions. In control wards the median QOD score was 7.0 pre and 6.0 post-intervention ($p=0.04$). Other scores were comparable with those in intervention wards.

Conclusions: Performing a complex intervention study in palliative care proved to be feasible. The study showed no differences in the experiences of bereaved relatives after introduction of nurse champions. The complexity of palliative care in the hospital might require more intensive and longer training of nurse champions.

Keywords: terminal care (MESH), family (MESH), hospitals (MESH), complex intervention, quality of dying, quality of life

Background

As hospital care focuses on cure and prolonging life, staff competence regarding palliative and terminal care is not necessarily a matter of course. Improving the quality of hospital end-of-life care is complex¹⁻³. Palliative care teams (PCT's) have been set up in many hospitals, to improve symptom control, psycho-social care and medical decision making. Recognition of palliative care needs of patients and of gaps in knowledge of the ward staff is a prerequisite for consultation of the PCT. Palliative care nurse champions might facilitate such consultation. In many healthcare settings, nurse champions are appointed to support the dissemination of specific knowledge and improve the quality of care. The effects of palliative care nurse champions in hospitals have rarely been evaluated. Studies in the UK reported that nurse champions themselves experienced increased knowledge on palliative care and felt more confident in collaborating with physicians and experts⁴⁻⁷. No study has evaluated the effects on quality of care as experienced by patients or their relatives. In general, experimental studies on quality improvement interventions in end-of-life care in the hospital are scarce⁸. Research in palliative care involves methodological and ethical challenges related to the complex nature of most interventions, ethical issues, and the risk of selection bias and confounding⁹⁻¹³. An intervention with nurse champions in the hospital involves changing processes and competencies and is therefore complex^{12,14}. Many factors may contribute to the effects. Effective processes of dissemination of knowledge, skills, and behaviours are a prerequisite for improved experiences of patients and their relatives.

This study investigates the effect of palliative care nurse champions on the quality of dying (QOD) in the hospital as experienced by bereaved relatives.

Methods

This study is part of a large study on Palliative and Terminal Care in the Hospital (PalTeC-H) in which we assessed and compared experiences of bereaved relatives, physicians and nurses; the study protocol and rationale of the design, assessments and endpoints are extensively described elsewhere¹⁵.

Setting and design

The study was performed in a 1300-bed Dutch university hospital. In the hospital a PCT was set up in 2006,

which has since then been consulted for 240 – 260 patients yearly.

We performed a controlled before-after study in 18 non-intensive care wards.. Halfway through the study, in 7 intervention wards (i.e. medical oncology and geriatrics, internal medicine, Ear, Nose & Throat surgery, gastro-intestinal surgery, gynaecology and urology, lung diseases, and cardiology) two nurses (estimated at 5-10% of nursing staff per ward) were appointed to become a palliative care nurse champion (hereafter referred to as: nurse champion). Data were compared before and after the introduction of nurse champions, and results were compared to outcomes in the same periods in 11 control wards in which the intervention was not applied. The pre-intervention phase lasted from June 2009 to October 2010 and the post-intervention phase from March 2011 to July 2012 (16 months each).

The intervention

Nurse champions were selected by ward managers, considering the nurse's motivation and competencies, and the availability within the nursing staff. In October 2010, the nurse champions became member of a palliative care nursing network. At least one nurse champion per ward was expected to participate in the monthly network meetings, where they discussed complex cases and situations related to their new roles and were taught about palliative care. Furthermore, they all attended a yearly two-day education program on palliative care. This program included various topics, such as symptom management, organisation of care, communication and performance skills, and care for the dying. Our main goal was to enable the nurse champions to identify gaps in knowledge and quality regarding palliative care on their ward, to raise ward staff's awareness of palliative care needs and indications for consulting the PCT, and to initiate care improvement programs, e.g. on the management of pain or delirium. The champions were coached to adapt various approaches for the implementation of their newly acquired knowledge. They were supported by the PCT and a senior nurse-specialist on palliative care. The latter coordinated the network, organized the meetings and education programs, and coached the champions individually to perform activities in their own wards.

Study population

For each adult patient who had died in the hospital after a hospitalisation of at least 6 hours, we included one close relative. An invitation was sent to the former address of the patient, or to the address of the close relative in case this was earlier provided to the ward nurse.

Ethical considerations

The study was approved by the Medical Ethical Research Committee of the hospital (MEC-2008-225).

According to Dutch regulation, written informed consent of patients was not required because we only collected observational data after the patient's death and the study involved minimal risk to the participants.

In case of emotional distress due to participation, participants were given the opportunity to call or meet the nurse investigator.

Questionnaire

We hypothesised that QOD in the hospital would be multidimensional including, e.g., physical, psycho-social and spiritual experiences, life closure and death preparation, and care processes¹⁵⁻¹⁷. End-of-life care was defined as care provided during the last three days of life. To comprehensively assess the perspectives of bereaved relatives, physicians and nurses for the PalTeC-H-project, three complementary self-administered questionnaires were developed, because previously described instruments did not meet these requirements¹⁸⁻²¹. Most items concerned the quality of care and quality of life in the final 3 days of life (QOL3), and quality of dying; three overlapping concepts that can be distinguished^{15,17,22}. Preliminary versions of the relatives questionnaire were critically evaluated by a representative of the hospital patient council, tested on relevance and face validity among persons who had recently lost a relative, and piloted in the first 30 cases. The final version of the questionnaire contained 93 items. Patient characteristics and the diagnosis cancer or non-cancer were derived from the medical file. In a study among 249 relatives we previously analysed which dimensions and items most determined the QOD according to relatives, i.e.] physical symptom burden (7 items), psychological symptom burden (7 items), acceptance of death (2 items), medical care and symptom management (4 items), shared decision-making (2 items), preparation on and circumstances of death (5 items), personalised care (5 items), and supportive care and care for relatives (4 items) (Box 1)²³.

Data collection

The relative was invited by the primary investigator (FEW), 10-13 weeks after the death, to participate in the study and complete the questionnaire. In cases of non-response, one reminder was sent after 4 weeks.

Participants could also ask the investigator to complete the questionnaire during an interview, e.g. in case of

illiteracy or visual impairment. Participants were informed about the general aim of the study (i.e. to assess the quality of dying and end-of-life care in the hospital),; but not about the intervention or study design.

Endpoints

Primary endpoints were relatives' global numerical scores (0-10) on QOL3 and QOD, asking "How would you evaluate the quality of life during the last 3 days of life of your relative?", and "How would you evaluate the quality of dying of your relative?", with 0 indicating "very poor" and 10 "almost perfect". Secondary endpoints were scores of previously mentioned domains²³.

Data analysis

To measure a difference of one unit on the QOL3 and the QOD scales between the pre- and post-intervention phase, with an assumed standard deviation of 2.5, we needed data on 400 patients: i.e. 100 patients both before and after the intervention, on both the intervention and the control wards¹⁵. Anticipating a participation rate of 50% among the relatives, we aimed to include 800 patients.

Domain-related items were recoded to dichotomous values: physical and psychological symptoms rated by relatives as "moderate" or "severe" were recoded to value 1; the answers "don't know", "none" or "mild" were recoded to value 0; For other items that could be answered as yes, no or don't know, value 1 was used for yes and 0 for the other two answers. Per domain we counted the values of the variables. Principal component analyses showed that the different variables per domain were similarly correlated, resulting in the same weight for all values. In the two symptom domains, a higher score indicated a lower QOD; , in the other domains a higher score indicated a better QOD. The mean value per domain was calculated. We compared outcomes of QOL3, QOD, and the mean domain values, pre- and post-intervention in the intervention wards. Subsequently, the findings were compared to outcomes in the same periods in the control wards. Data were analysed with t-tests, Mann Whitney-U tests, and Pearson's Chi-square tests, using SPSS data analysis software, version 21.

Results

During the study period 818 patients (equally distributed between pre- and post-intervention assessment) died: 351 in intervention wards and 467 in control wards. Relatives of 49 deceased patients (6%) could not be

traced and in three cases healthcare staff had objections against asking the relative to participate. A questionnaire was sent to 761 relatives; 396 (52%) participated, i.e. 170 in the intervention wards (86 pre- and 84 post-intervention) and 226 in the control wards (108 pre- and 118 post-intervention). One participant requested a face-to-face interview to fill out the questionnaire. The patients reported on were older than patients of whom no relative participated (68.5 vs 65.5 years; $p=0.006$). No differences were found between responders and non-responders for patients' gender, and duration and ward of the last hospitalisation.

Characteristics of patients and relatives

A majority of patients was male, lived in partnership until last admission, and had been ill for ≥ 6 months (Table 1). Relatives were most often the partner or child of the patient. On average, relatives completed the questionnaire 15.6 weeks (sd 5.8) after the patient's death. Some of the characteristics differed slightly between the pre- and post-intervention assessment, e.g. the patient's and relative's age, and the duration of hospitalisation.

Implementation

The seven intervention wards appointed 14 staff nurses to become nurse champions. They received four days of education and, on average, participated in 8.2 of the 18 network meetings. Five nurse champions prematurely left the network, in case of three due to a new position elsewhere and were replaced by others.

Effects on QOL3 and QOD

In the intervention wards the median QOL3 score was 3.0 both pre- and post-intervention (mid-80% range [10th-90th percentile] 0.2-7.0, and 0.0-7.0, respectively) ($p=0.92$) (Table 2). The median QOD score was 7.0 in both phases (mid-80% range 2.0-10.0, and 1.0-9.0 respectively) ($p=0.57$). In the control wards the median QOL3 score also was 3.0 during pre and post-intervention assessment (mid-80% range 0.0-8.0 both) ($p=0.20$). The median QOD pre-intervention was 7.0 (mid-80% range 1.3-9.0) and post-intervention the median was 6.0 (mid-80% range 0.0-9.0) ($p=0.04$).

Effects on domains of QOD

Relatives reported that, during the final 24 h, patients had moderately to severely suffered from 2.5 of 7 physical symptoms, and from 2.0 of 7 psychological symptoms; no differences were found between pre and post-intervention assessment (Table 3).

Also scores in the other domains, i.e. of acceptance of death, medical care and symptom management, shared decision-making, preparation on and circumstances of death, personalised care, and supportive care and care for relatives, did not differ pre- and post-intervention.

Discussion

We found no improvements in the QOL3 and QOD as experienced by bereaved relatives. Patient or relative-reported outcomes of care in the last days of life are seldom investigated. A few experimental studies to improve cancer care did not result in improved care as evaluated by patients or relatives²⁴. No comparable studies were found on the effect of nurse champions on the quality of life at the end of life or quality of dying, as experienced by relatives or patients.

In the control wards, during post-intervention assessment, relatives more often evaluated the QOD as (very) poor, compared to the pre-intervention assessment. These findings cannot easily be explained. We made no in-depth study of the care processes in the control wards, but relatives reported slightly (but not significantly) increased psychological symptom burden and dissatisfaction on medical treatment and symptom management. Another explanation might be the development in Western societies towards empowerment of the general public and of patients, which might be reflected in increased expressions of dissatisfaction in society in general and in healthcare in particular²⁵. The fact that the median QOD score in the intervention wards post-intervention was similar to the pre-intervention assessment, might cautiously be interpreted as an effect of nurse champions.

Although the questionnaires and assessment procedures differed, our scores on QOD might (to some extent) be comparable to the outcomes of two recent studies assessing the total Quality of Dying and Death (QODD) score (rated on a 0-100 scale) among relatives of patients who died in 'acute' hospitals. In Italy, the mean QODD in the control wards of a cluster randomised trial on the Liverpool Care Pathway (LCP) was 63²⁶. In

Canada the QODD in various settings was on average 65 and hospital deaths were associated with lower scores²⁷.

In our study, in all wards relatives scored the QOL3 with a median of 3.0. Such a low score might not be surprising, as patients in the last days of life are confronted with suffering from symptoms and deterioration of health, strongly affecting their quality of life. Nevertheless, this score must be cautiously interpreted as it was rated by a relative; relatives may tend to overestimate the severity of symptoms and problems when compared to the evaluation of patients and healthcare professionals²⁸⁻³².

Our study showed no differences between pre- and post-intervention, which may be due to several factors. Firstly, in this complex intervention many aspects may contribute to the effects, including knowledge, skills and attitudes of the nurse champions and of the ward staff, and the complex nature of end-of-life care in a teaching hospital.^{13,14} Secondly, a network of nurse champions is an organisational model primarily aimed at enabling and supporting optimal processes of care³³, the effect of which may not be recognised by patients or relatives^{24,26}. Thirdly, the intervention was based on the indirect transfer and dissemination of knowledge of palliative care experts to the wards, i.e. via nurse champions. Such a model has advantages when compared to direct teaching ward teams by experts, e.g. because the nurse champions might be more motivated than other team members to learn from the experts, and they have better insight into the ward culture and more implementation opportunities than the experts^{15,34,35}. To be effective, however, nurse champions needed first to adapt to new knowledge and skills themselves, then to incorporate these in their behaviour and then to disseminate these to the teams^{36,37}. Subsequently, ward staff needed to put newly derived knowledge and skills into practice. Obviously, these processes were at risk for disturbance and barriers. Fourthly, end-of-life care should be multidisciplinary care and nurse champions might have had difficulties in assuming their roles and discussing goals of treatment and care with other team members, especially the physicians. Empowerment of nurse champions has been suggested to be essential for good performance⁹⁻¹³. Fifthly, the performance of the intervention depended strongly on the activities of nurse champions in their ward, who needed to apply multiple strategies³⁸. The nurse network facilitated champions to share knowledge, and to capture knowledge and skills from outside their wards. However, they were not used to working in a network and it might have taken additional time to benefit from this model, and to internalise improving strategies. Moreover, the turnover of nurse champions implied periods of non-activity and delay. Finally, the design and

process of the study might have limited our findings; our study was slightly underpowered in the intervention wards. The education program had to be planned ahead to enable nurse champions to participate and, in hindsight, we received less than the planned number of questionnaires. In addition, we planned a 5-month period for nurse champions to take up their role and assumed further incremental growth after the start of the post-intervention assessment. However, the complex nature of palliative care requires advanced knowledge, skills and attitudes and nurse champions probably needed more time before being able to make a difference in the experience of relatives. Furthermore, we only assessed their effect on care in the last days of life, while the intervention was aimed at improving care during the entire palliative phase.

Despite the equal findings in relatives' experiences, we believe that nurse champions might contribute to the awareness of palliative care needs and of shortcomings in care, and also to the role of nurses in the multidisciplinary team. The shift from curative to palliative and terminal care implies a larger role for nurses, e.g. in comfort care, end-of-life communication and decision-making, and the support of relatives. Nurses need to take up this role and improve their knowledge, skills, confidence and performance^{2,3,39-43}. This is challenging in the hospital, e.g. because of the focus on cure and the low prevalence of end-of-life care, the complexity of care, the ethical dilemmas and emotional difficulties^{2,44,45}. Continued education of all nurses does not seem to be cost-effective; therefore, a model with nurse champions might facilitate nurses to meet the requirements^{5,7,33}. However, nurse champions need to be acknowledged, facilitated and supported by, e.g., the PCT and ward management. Furthermore, improvement of end-of-life care requires multiple strategies and has to go beyond the appointment of two nurse champions on the ward³⁸.

Conclusion

This study showed no effect of the introduction of palliative care nurse champions on the experiences of relatives regarding the QOL3 and the QOD of patients dying in hospital. However, also no worsening was found, as was seen in the control wards.

Moreover, we showed that experimental research in the organisation of end-of-life care is feasible. With a response rate of 52%, bereaved relatives showed their willingness to participate. Good planning, commitment of management, and the support of the PCT are essential elements of the implementation of the intervention.

Future research on nurse champions should take into account a longer 'running-up' period and to empower the nurses to take up their role.

Disclosures and Acknowledgments

All authors declare that they have no competing interests; they all declare to have full access to all of the data (including statistical reports and tables) in the study and can take responsibility for the integrity of the data and the accuracy of the analysis. FW and AH have been responsible for the conduction and the analysis of data. This study was financially supported by a grant from the Erasmus MC Medical Research Committee and the Tom and Josephine Rijckes legacy foundation, and both did not have any involvement in the design and conduct of the study; collection, management, analysis, and interpretation of the data; and preparation, review, or approval of the manuscript. We thank the hospital patient council for their critical advice and support.

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Box 1: Domains of Quality of Dying

Domains	Topics
Physical symptom burden	Pain Dyspnoea Dry mouth Trouble sleeping Fatigue Nausea Agitation
Psychological symptom burden	Anxiety Loneliness Tenseness Sadness Powerlessness Worrying Depressive mood
Acceptance of imminent death	Patient being in peace with imminent death Patient being aware of imminent death
Medical treatment and symptom management	Alleviation of symptoms Staff's efforts to alleviate symptoms and problems Relative being informed on imminence of death In hindsight, evaluation of hospital as right place of death
Preparation on and circumstances of death	Relative being aware of imminent death Attention to hospital facilities and wishes of patient and relatives Relative being present at moment of death

	Relative saying goodbye
	Patient saying goodbye
Shared decision-making	Patient participation in nursing care decisions
	Patient participation in medical decisions
Personalised care	Affirmation of the patient as a person
	Attention to preferred rituals at moment of death
	Opportunities to discuss personal or religious preferences
	Patient having discussed preferences on EoL treatment
	Social and spiritual support last 24 h.
Supportive care and care for relatives	Relative participation in nursing care decisions
	Relative being informed about condition and care
	Relative participation medical decisions
	Nursing care final 24 h.

Table 1: General characteristics

		Intervention wards ^a (N=167)			Control wards ^b (N=215)		
		Pre- intervention <i>n</i> =86	Post- intervention <i>n</i> =84	Difference pre-post ^c (<i>p</i> -value)	Pre- intervention <i>n</i> =108	Post- intervention <i>n</i> =118	Difference pre-post ^c (<i>p</i> -value)
Age in years; mean (SD)		69 (12)	68 / 13	0.81	67 (17)	70 (13)	0.08
Gender	Male	54 (63)	53 (63)	0.97	60 (56)	65 (55)	0.91
	Female	32 (37)	31 (37)		48 (44)	53 (45)	
Marital status	Married/living with a partner	49 (57)	58 (70)	0.10	65 (60)	79 (67)	0.42
	Widowed/Divorced/Living alone/Other	37 (43)	26 (30)		43 (40)	39 (33)	
Children	One or more children < 19 years	9 (11)	5 (6)	0.21	7 (6)	11 (9)	0.23
	Only children ≥ 19 years	63 (73)	57 (68)		69 (64)	83 (71)	
	No	14 (16)	22 (26)		32 (30)	24 (20)	
Education	Low (ISCED level 1-2)	29 (34)	25 (30)	0.79	31 (29)	41 (35)	0.47
	Intermediate (ISCED 3-4)	33 (38)	34 (41)		40 (37)	42 (35)	
	High (ISCED 5-6)	14 (16)	11 (13)		24 (22)	23 (20)	
	Other/ unknown	10 (12)	14 (17)		13 (12)	12 (10)	
Religious	Yes	42 (49)	41 (50)	0.87	56 (52)	69 (59)	0.13
	No/ unknown	44 (51)	43 (50)		52 (48)	59 (41)	
Diagnosis ^d	Cancer	47 (55)	51 (61)	0.47	42 (39)	57 (48)	0.16
	Non-cancer	39 (45)	33 (39)		66 (61)	61 (52)	
		6 (7)	8 (10)	0.83	21 (21)	25 (22)	0.83

Effects of nurse champions according to relatives

Duration of severe illness	< 1 month	26 (31)	24 (29)		19 (19)	25 (22)	
	≥1 and ≤ 6 months	52 (60)	52 (62)		63 (60)	61 (52)	
	> 6 months						
Wards	Non-surgical wards	65 (76)	63 (75)	0.96	83 (77)	90 (76)	0.87
	Surgical wards	21 (24)	21 (25)		25 (23)	28 (24)	
Duration last admission in days: mean / SD		17.0 / 24.0	14.3 / 14.5	0.34	17.8 / 23.4	13.2 / 13.2	0.05
Relatives							
Age in years: mean / SD		55 / 13	58 / 14	0.08	55 / 12	58 / 14	0.11
Gender	Male	26 (30)	29 (35)	0.62	39 (36)	47 (40)	0.53
	Female	59 (70)	55 (65)		69 (64)	70 (60)	
Relation	Partner / spouse	38 (44)	46 (55)	0.25	44 (41)	66 (56)	0.05
	Child (in law)	32 (37)	21 (25)		39 (36)	37 (31)	
	Other	16 (19)	17 (20)		25 (23)	15 (13)	

^a Intervention wards: Cardiology; Ear Nose & Throat surgery; Gastro-intestinal surgery; Gynaecology and urology; Internal Medicine – infectious diseases and endocrinology; Lung diseases; Medical oncology and geriatrics

^b Control wards: Haematology; Internal medicine- gastro intestinal diseases; Internal medicine– renal diseases; Neurology; Neurosurgery and brain surgery; Liver and kidney transplant and vascular surgery; Orthopaedics; Plastic surgery and dermatology; Trauma surgery; Thorax surgery; Palliative oncology

^c Pearson's Chi² tests

^d diagnosis derived from patient record

Table 2: Effects of intervention on Quality of Life (QOL3) during last 3 days of life and Quality of Dying (QOD)

QOL3 and QOD	Intervention wards			Control wards		
	Pre-	Post-	Difference	Pre-	Post-	Difference
	intervention	intervention	pre-post ^a (<i>p</i> -value)	intervention	intervention	pre-post ^a (<i>p</i> -value)
Quality of life during last 3 days: median (mid-80%)	3 (0.2-7.0)	3 (0.0-7.0)	0.92	3 (0.0-8.8)	3 (0.0-8.0)	0.20
Quality of dying: median (mid-80%)	7 (2.0-10.0)	7 (1.0-9.0)	0.57	7 (1.3-9.0)	6 (0.0-9.0)	0.04

Mid-80% = mid-80% range (10%-90%)

^a Independent samples Mann-Whitney U-test

Table 3: Effects of intervention on domains of QOD

Domains	Intervention wards			Control wards		
	Pre- intervention	Post- intervention	Difference (<i>p</i> -value) ^a	Pre- intervention	Post- intervention	Difference (<i>p</i> -value) ^a
	Mean (SD)	Mean (SD)		Mean (SD)	Mean (SD)	
Physical symptoms (0-7) ^b	2.7 (1.8)	2.8 (1.7)	0.86	1.8 (1.7)	1.9 (1.9)	0.91
Psychological symptoms (0-7) ^b	2.5 (2.7)	2.4 (2.7)	0.59	1.4 (2.1)	1.7 (2.4)	0.21
Acceptance of imminent death (0-2) ^c	0.7 (0.7)	0.7 (0.8)	0.92	0.6 (0.8)	0.7 (0.8)	0.26
Medical treatment/ symptom management (0-4) ^c	2.3 (1.3)	2.2 (1.3)	0.86	2.6 (1.3)	2.2 (1.3)	0.15
Preparation on / circumstances of death (0-5) ^c	3.0 (1.6)	2.9 (1.7)	0.27	2.9 (1.5)	2.7 (1.6)	0.41
Shared decision-making (0-2) ^c	0.9 (1.0)	0.9 (0.9)	0.57	0.8 (0.9)	0.9 (0.9)	0.37
Personalised care (0-5) ^c	2.1 (1.4)	2.1 (1.4)	0.94	2.2 (1.4)	2.4 (1.3)	0.75
Supportive care/ care for relatives (0-4) ^c	2.9 (1.4)	2.6 (1.5)	0.33	3.0 (1.3)	3.0 (1.3)	0.94

^a Pearson's Chi² test^b Higher score indicates more symptom burden^c Higher score indicates more satisfaction